

2011 Neil Samuel Ghiso Foundation Fellowship Report

Fellow: Betsy Campbell

Project: Writing a draft of *Who Cares* – a Piece of Documentary Theater about End-of-Life Caregivers in Contemporary America – while participating in a Summer Program on Bioethics at Yale University

As a Ghiso Fellow, I participated in the 2011 Summer Program at the Yale University Interdisciplinary Center for Bioethics. My time on campus was busy: I attended daily lectures and seminars taught by Yale faculty; I wrote and presented a paper about positive psychology at the end of life; and I published a poem in the Yale Journal of Humanities in Medicine. However, my main project was to develop a piece of documentary theater about the experiences of end-of-life caregivers. I successfully crafted a draft of the script, cast accomplished actresses for the parts, staged a reading of the script for members and friends of the Yale University Interdisciplinary Bioethics Center, and facilitated a set of discussions about caregiving.

Without the generous support from the Neil Samuel Ghiso Foundation I would not have been able to attend the Yale University summer program. This report details: 1) my formal learning experiences at Yale University; 2) the documentary theater project; and 3) the public dialogue facilitation. The report also mentions highlights from the evaluation of my project. And finally, the report describes some next steps for my project.

Formal Learning Experiences

In addition to a daily lecture on a bioethics topic with the entire cohort, I attended small seminars including Basic Bioethics, taught by Dr. David Smith, Aging, taught by Dr. Howard Spiro, and End-of-

Life Issues, managed by Carol Pollard. The lectures and seminars exposed us to many issues and perspectives in bioethics. They also provided us with opportunities to discuss these topics with leaders in medicine, theology, philosophy, law, and the humanities.

These formal educational opportunities sharpened my understanding of the history of bioethics and the enduring principles that guide it. I also gained new appreciation for the cultural complexities of bioethical matters. This heightened awareness informed my thinking and influenced a piece of documentary theater that I am writing – the independent project that was the focus for my Neil Samuel Ghiso Foundation Fellowship.

Documentary Theater Project

Since the end of 2010 I have been recording oral histories of people who participate in providing palliative care at the end of life. At Yale I began to examine these narratives and use them to create a piece of documentary theater about end-of-life caregiving. (Documentary theater uses factual material – such as interviews – as the source material for the script, ideally without altering any words or meanings.) The tentative title for the play is *Who Cares*.

Given the limited time of my Fellowship and the Yale program I focused on a subset of the oral histories in my growing collection. I transcribed and edited five narratives into monologues suitable for performance. Simultaneously, I reached out across the university to the Yale School of Drama and the Yale College Department of Theater Studies to help me cast the roles. Eventually the monologues were ready, and I selected some accomplished actresses – Connie Grappo, Anne Twomey Lloyd, Sarah Peterson, and Kate Staton – to present them in a public forum on campus.

On the evening of July 27th members of the Yale Bioethics community gathered to listen to the first

reading of excerpts from *Who Cares*. In attendance were faculty members and many students enrolled in medical school, divinity school, and law school. The actresses presented the monologues as originally stated by four Certified Nursing Assistants and one Hospice Chaplain. The monologues conveyed the everyday experiences of these workers and touched on important issues of race, class, gender, age, and opportunity.

Public Dialogue Facilitation

After we thanked the actresses for their reading of the monologues, I guided the group in a discussion about the issues raised by the excerpts from *Who Cares*. I used a bottom-up format for guiding group learning; the process enables participants to select the topics that they most want to discuss. The members of the Bioethics community suggested topics – the role of love in end-of-life caregiving, the reason why caregiving tends to be women's work, the ways that a caregiver's spirituality or world-view might be affected by the care-giving experience, and others – and broke into small groups for 30 minutes of conversation. Following the 30-minute small-group discussions, the larger group reconvened and shared headlines from the small-group discussions. A brief discussion as a large group followed.

Evaluation

At the conclusion of the reading and the discussion, I asked all participants to complete a short evaluation of *Who Cares* and the group dialogue format. The feedback was overwhelmingly positive. People were surprised at the range of issues that caregivers face on the job and because of their job. People were moved by the stories and had not expected the range of emotions that they felt. They also enjoyed the bottom-up selection of topics for discussion; this format ensured that people were engaged in the conversation(s). The criticisms included a wish for the actresses to participate in the dialogues, and for more time to discuss the issues when the large group reassembled. One participant asked when

I would be ready to produce *Who Cares* for other audiences, and if I would be willing to showcase it at a particular university where he is affiliated.

My own assessment of the process and presentation is largely positive. I met my goals for the summer given the limited time and resources. If I had the experience to do again I would select a different venue for the presentation, strive to have more rehearsal time with the actresses, and provide for a modest reception after the event to round out the evening a bit better. I would also make one production change: I would project a few specific pieces of background information about the original caregivers behind the actresses as each monologue was read. (I did project information, but in hindsight it was too much detail. The monologues spoke for themselves.)

I was quite fortunate to get to do this work at Yale and specifically at the Yale University Interdisciplinary Center for Bioethics. The contact with faculty, alumni, staff, and students from across the university – Yale School of Medicine, Yale School of Nursing, Yale School of Drama, Yale Divinity School, and the undergraduate College – was exciting and extremely beneficial.

Looking Forward

I am continuing to gather oral histories from people who work in palliative care at the end of life and to prepare these narratives for use in this piece of documentary theater. Upon the completion of *Who Cares*, I intend to make the script and a discussion guide available online (and possibly in print). My hope is that these monologues and their performances will inspire public dialogue about palliative care – and the experiences of the people who provide that care – at the end of life.

To do this work I will need to find additional financial support. I am grateful to the Harvard Medical School and the Neil Samuel Ghiso Foundation for their vision and support at this early stage of my

project. Without their assistance I would not have been able to attend the Yale University summer program nor develop *Who Cares* to its current level of completion. Moreover, without their support I would not have been able to inspire audience members in New Haven to explore the important issues about caregiving raised by *Who Cares*.

Having had these experiences, I am more confident of the power of documentary theater for raising important issues. I am also more certain about the need for public dialogue about caregivers' experiences as they provide palliative end-of-life care. And I am more driven to harness the power of the medical humanities to stimulate awareness about palliative end-of-life care.

Receiving the Neil Samuel Ghiso Foundation Fellowship has made a significant difference in my work. And the Fellowship, through the initial production of *Who Cares*, has already begun to impact the lives of others. As I develop and disseminate the script, more people in more places will become aware of the value of palliative care and the contributions of the people who provide it to patients near the end of their lives. Over time, I hope that my work can help the Ghiso Foundation meet its goal of exposing medical students (and others) to the importance of compassionate care.